Babies with Birth Defects

A REFERRAL GUIDE FOR MICHIGAN HOSPITALS



2007

At a time when many new parents of babies with birth defects are feeling most alone, worried, and vulnerable, hospitals can play a critical role in helping them find services and support through community-based programs and systems.

This booklet provides some suggestions on how Michigan hospitals can help families of babies with special health needs <u>before</u> discharge find and enroll in the services that will provide support <u>after</u> discharge. We hope this information will help to reinforce the important role that hospital-based care providers play in helping to assure a smooth transition from hospital to home.

Providing referral information before hospital discharge helps to empower families in establishing a medical home for their child, and facilitates earlier entry into services that may help reduce the impact of secondary disabilities on both the child and family.



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Purpose

The purpose of this booklet is to bring attention to the importance of linking families of children with birth defects and heritable disorders to community-based services and a medical home. Hospital-based health care professionals play an important role in helping families find the services they need to care for an infant with special health or developmental needs after leaving the hospital. The guidelines presented here are based on a compilation of best practices observed by Michigan Birth Defects Registry staff in visits to 20 hospitals over a two-year period. While a variety of referral methods were observed, the best practices were

characterized by systems that promoted routine collaboration, communication, and written documentation by hospital-based caregivers, including social workers, physicians, nurses and clergy. Best practice referral systems assure that every child

with potential special needs, regardless of the specific diagnosis, is identified and referred to local service and support programs. Some of the key resources available throughout the State of Michigan are described further in the back of this booklet.

The Medical Home

The American Academy of Pediatrics advocates that all children with special health care needs, including birth defects, receive care through a medical home. The medical home is not a specific site but is characterized by an optimal level of care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. Ideally, the primary care physician works with a family to coordinate medical subspecialty care and community-based services to help meet the child's special needs. This booklet suggests ways that hospital staff can help families of children with birth defects and heritable disorders

start to build a medical home. Michigan's Children's Special Health Care Services (CSHCS) Program is working to establish regional systems of care for children with special health care needs that depend not only on tertiary care centers but also on having a medical home and services available in local communities. Hospitals can help by assuring that all infants with special health needs have an identified medical home, and by promoting *early* referral and enrollment in community-based systems of care prior to hospital discharge. The earlier a medical home is established, and a child with special needs is referred to services and

enrolled, the more seamless and coordinated is the care that can be provided. Thus, the role of *inpatient* referral to specialized service programs such as CSHCS, Family Support Network (FSN), *Early On*®

and the Medicaid Maternal Infant Health Program (MIHP-- formerly Maternal Support/Infant Support Services) cannot be over emphasized.

Background

Hospitals can help by assuring that all

infants with special health needs have an

identified medical home, and by promoting

early referral and enrollment in

community-based systems of care. For

more information on medical home, visit

www.medicalhomeinfo.org

The Michigan Birth Defects Registry (MBDR) recently completed a study examining referral patterns for children from birth through two years of age who had been reported to MBDR. From 2001-03, MBDR staff visited 20 hospital facilities, including minor and major obstetrical care centers, hospitals with regional neonatal intensive care units (NICU), and major referral centers throughout the state. They abstracted the inpatient health records of 825 children with a variety of serious birth defects including chromosomal syndromes, neural tube defects, craniofacial anomalies, and disorders of the musculoskeletal and circulatory (heart) systems.

Any information in the record documenting referral to services was noted. The number

of referrals for any individual child ranged from zero to more than 10. Overall, 699 children (84.7%) had one or more documented referrals. The types of referrals included *inpatient* specialty care (such as orthopedic surgery, cardiology or endocrinology), *outpatient* specialty care (such as genetics or pediatric specialty clinics) and *public health* or other *community-based* services. Of the referrals documented, 60.2% originated from physicians, 17.5% originated from social workers and 19.1% originated from discharge planners.

The most common referral types were for inpatient specialty consultation or outpatient specialty clinics. In contrast, the number of documented referrals to community-based services that might assist a family after hospital discharge with the non-medical aspects of a child's care was much lower.

For instance, referral to Early On® (Michigan's early intervention system for infants and toddlers) was present in only 139 of the 699 health records (19.9%); referral to Children's Special Health Care Services (CSHCS)

was present in 20.2% (141 of 699) of the health records; and referral to the Supplemental Nutrition Program for Women, Infants and Children (WIC) was present in about 10% of the charts (72/699).

Although it appeared that each hospital facility linked families with services a little differently, some general patterns were observed:

- Children with conditions reportable to MBDR were well linked with medical referrals for inpatient consultations and specialty care, as well as for outpatient specialty care.
- Referrals to services for transitioning child and family from hospital to home and the community were documented less often in the health record. Although it is possible they are still occurring, there appears to be a need for more

emphasis on connecting families with these services.

- Physicians most often made referrals to medical specialists.
- Social workers and discharge planners most often made referrals to public health or community-based services and programs.
- The same child may have received multiple referrals from different sources (physician, social worker, discharge planner) and/or multiple referrals from the same source.
- Children referred to the CSHCS program during the inpatient admission were enrolled and began receiving benefits from the program at a younger age than those referred from an outpatient setting after discharge.

In contrast (to the medical referrals) the number of referrals to community-based



Commonly Asked Questions

What is a birth defect?

- A birth defect is an abnormal condition that occurs before or at the time of birth.
- Some birth defects are minor—like an extra finger, while others are life-threatening—such as a serious heart defect.
- Some birth defects are caused by genetic factors; others are the effect of exposure to certain drugs, medications, chemicals or infectious agents—but most result from a combination of genetic and other factors.
- The causes of many birth defects are still a mystery.
- Examples of birth defects include:
 - · Cleft lip and palate
 - Chromosomal disorders such as Down syndrome, Trisomy 13 or 18
 - Fetal Alcohol Spectrum Disorders
 - Genetic syndromes such as Angelman, Beckwith-Wiedemann or Prader-Willi syndrome
 - Hearing loss
 - Microcephaly
 - Neural tube defect (NTD) such as spina bifida
 - Omphalocele
 - Skeletal dysplasia or dwarfism

How common are birth defects?

- About 3-4% of liveborn infants are affected by a serious birth defect.
- Between 9,000 and 11,000 babies with birth defects are reported to the Michigan Birth Defects Registry (MBDR) each year.
- Heart defects are the most common type of birth defect.

Why are birth defects a public health concern?

- Birth defects are the leading cause of death in children—causing 1 in 5 deaths in babies through 12 months of age and as many as 40% of deaths in children through the age of 10 years.
- Birth defects are also a significant cause of childhood morbidity and long-term disability.
- Children with birth defects often require care that is expensive and highly specialized.
- Birth defects often impact family dynamics resulting in additional financial pressures, marital discord, and concerns about the needs of siblings.
- Some birth defects can be prevented through public health prevention efforts, such as promoting folic acid intake to reduce the risk of neural tube defects.

What types of services do families often need?

- Advocacy
- Early intervention and special education
- Emotional and spiritual support
- Financial assistance
- Home care
- Hospice
- Insurance

- Legal assistance
- Medical equipment/supplies
- Medical services
- Mental health and/or behavioral services
- Prevention information
- Respite care
- Transportation

What role can hospital staff play in referring families to services?

- Provide information on services and support systems like CSHCS, FSN, Early On® or MIHP
- Recommend appropriate services and referrals **EARLIER** than waiting until after discharge, enabling earlier enrollment and service delivery
- Empower families to ask questions about services their child may need after discharge, and to request referrals as appropriate
- Document referrals or service information provided to the family in progress notes or on the appropriate form in a baby's health record
- Educate colleagues about community-based services if your facility requires certain individuals to initiate referrals

Who should be responsible for making referrals that link babies and families to services?

This may vary by hospital, but it is important for every nursery to have a protocol in place to assure that **someone** is designated to assume this responsibility. Personnel who typically discuss referrals may include:

- Care coordinators
- Clergy members
- Discharge planners
- Family coordinators
- Nurses/ Nurse practitioners
- Parent consultants
- Physicians
- Social workers

Often, just one person can make a big difference by providing information about available resources, or empowering a family to ask about services their child may need after discharge.

Outstanding Referral Practices

A variety of protocols and procedures were observed across the state. Examples of "best practices" found in three different hospitals for linking children with birth defects to intervention services are described below.

Hospital A does an excellent job of linking children and their families with services. All NICU babies receive automatic referral to the unit's social worker, who provides comprehensive care coordination through teleconferences with local health departments and homecare nursing providers prior to discharge. These teleconferences are intended to link the family. medical specialists, and caregivers in the community to one another, often across many miles of rural Michigan. Most notably, babies with birth defects are not only referred but often enrolled in CHSCS and Early On® prior to hospital discharge. This facility is a model for successfully linking families with services despite geographic challenges and small numbers of medical specialists compared to other areas of the state.

- Hospital B provides tertiary care to some of the region's sickest newborns while also having close ties with two of the state's pediatric hospitals located in southeast Michigan. Referrals are clearly documented in all hospital health records, including physician referrals to local public health services along with the expected consults/referrals for specialty care both in the hospital and after discharge. The hospital not only serves babies and their families during hospitalization, but also demonstrates a commitment to preparing them for discharge to services in the community.
- Hospital C exhibits collaboration and follow-through within a tertiary health care center to assure provision of relevant genetic information and linkage with the medical home. Neonatology staff collaborates with other sub-specialists including medical genetics. A medical geneticist was called to meet with the family of a newborn with a neural tube defect (NTD) and explain the nature of the birth defect, interventions required, and possible causal pathways.
- After providing information and support, the physician also explained the role of folic acid in reducing the risk of NTD recurrence in future pregnancies for this mother. Not only was this issue *discussed* but it was also thoroughly *documented* in the child's health record. In the case of a baby with Down syndrome, the geneticist gave the baby's parents as well as the child's pediatrician a copy of the American Academy of Pediatrics Health Supervision Guidelines for Children with Down syndrome AND documented these activities in the health record. The parents were also given contact information for another family in their community who was willing to provide family-to-family support.

- All NICU babies referred to a social worker
- Routine teleconferences with community-based service providers before discharge
- Enrollment in *Early On®* and *CSHCS* before discharge

- Complete, written documentation in hospital records
- Physician referrals for outpatient care and local public health services after discharge

- Referral for inpatient genetics consultation
- Provision of written health guidelines
- Referral for family-to-family support

Overcoming Challenges to Referral

The following case studies provide examples of common barriers to best referral practices, where newborns with birth defects were *not* referred to services or supports before hospital discharge. The examples illustrate relatively common scenarios where multiple factors contribute to missed opportunities for linking children with community-based services. Of special concern are the many children with birth defects whose future service needs escape attention because of the non-life threatening nature of their condition.

Case Study #1

Baby Boy Smith was born on a Saturday at a rural Michigan hospital. Although he was otherwise healthy, a diagnosis of Down syndrome was made at four hours of age based on

physical characteristics. A karyotype was ordered to confirm the diagnosis. As he did not require any special medical care before discharge on a Sunday afternoon (when social work coverage was unavailable), his parents received no information from hospital personnel on where to turn for help in raising their son with special needs. Baby Smith had fallen through the "referral net". In the best practice scenario, the family should have received referral to Early On®, literature about Down syndrome and/or an outpatient genetics consultation for more information if desired, and support groups in the region serving families of children with Down syndrome.

Fvaluate nursery and NICU discharge protocols to assure provision of information and referrals for all infants with special health care needs regardless of time and day of the week

Case Study #2

Baby Girl O'Connor was born six weeks prematurely with an absent kidney. Baby required extra care in the newborn nursery including oxygen, IV therapy, and ultrasound evaluation but did not require transport to a tertiary care facility for surgery or more intensive medical

intervention. Attending staff were able to stabilize her condition and she was discharged at five days of age. However, with the focus on this preemie's acute medical needs, the family never received information on early intervention services in their community.

Case Study #3

Baby Girl Young was born with a major cardiac defect requiring immediate transfer to a major medical center. Mom remained in the birthing hospital 200 miles away, receiving medical updates on her daughter's surgery by telephone. Because of the critical and acute nature of the

✓ Identify strategies to overcome communication barriers when parents are far away. Consider providing packets of standard referral information and conference calls with families to discuss referral needs

baby's birth defect, specialty care understandably focused on preserving the infant's life rather than the parents' needs. Because of the distance involved, family members were able to visit only sporadically, and the visits that did occur were consumed with teaching mom and dad how to care for the baby's medical needs. By the time baby was well enough for discharge several weeks later, the need to link the family with a local support network had been overlooked.

Addressing issues such as day/time of discharge, assessment of long-range educational and financial needs, and availability of printed resource materials at all times are just a few of the elements that contribute to the process of linking families to information that can assist them as they prepare for life outside of the hospital.

- Establish a written protocol that outlines procedures in the NICU, newborn nursery and mother-baby unit to assure that families receive resource and referral information.
- Use a standard form/check list in the baby's health record for tracking service referrals and resource information provided (see sample Universal Referral Form).
- Document clearly, in writing, any referral information shared with a family in the baby's (and/or mother's) health

 How can health

record.

 Find out more about state and local programs serving children with special health care needs.

They often provide in-service trainings as well as written materials to share with families (see list of key programs for contact information).

- Maintain a supply of pamphlets and educational materials about communitybased services and other resources.
 Make sure they are readily available to FAMILIES in the newborn nursery, special care nursery, NICU, PICU and pediatrics unit.
- Arrange in-service trainings for medical and nursing personnel, and support staff members who want to learn more about available services and program eligibility. Include resource and referral information in orientation procedures for new employees.
- Assure that nursery staff from different disciplines and across all shifts know how the referral process works in your hospital and are familiar with the roles of social work, care coordination or discharge planning staff, so that anyone

- involved in caring for a baby with birth defects knows WHO TO ASK and HOW TO HELP the family find services before and after discharge.
- Learn more about medical home for babies with special health needs and reinforce with parents the role that families play in building a medical home for their child after leaving the hospital.
- 9. Refer families to parent-to-parent support networks available in your

hospital, community, or the statewide Family Support Network so they can learn from others who have shared similar experiences.

10. If possible, find out about the Local Interagency

Coordinating Council (LICC) in your hospital's area to learn more about the larger system of care and community supports available to children with special needs and their families.

In the NICU

- 11. Start to plan early in hospitalization for a baby's **long-term needs** after discharge.
- Make a social work referral as soon as possible for assessment of family strengths and areas of need.
- Assess a family's changing needs for services and support through regular (daily/weekly) updates from charge and staff nurses caring for the patient.
- 14. Conduct weekly multidisciplinary care conferences that include the family, and identify community-based services that might be helpful as part of the discussion.

How can hospitals help link

families of babies with

special health care needs

to resources and services?

Learn about Michigan services and support systems

1. Children's Special Health Care Services (CSHCS) Program

- Free web-based education module: Visit www.training.mihealth.org/ and scroll down to the "New Featured Courses" section; click on the link to "What is Children's Special Health Care Services?"; then click on the "Sign Up" button to register as a site user.
- **CSHCS 101 In-Service Training** includes information on the referral process, eligible conditions, local contacts, Family Center for Children and Youth with Special Health Needs and Family Support Network (FSN). Contact the Family Center at 1-800-359-3722 or e-mail cshcsfc@michigan.gov.
- **To make a referral:** contact the CSHCS coordinator at the local health department in the child's county of residence or call the CSHCS toll-free Family Phone Line at 1-800-359-3722 for information on how to initiate a referral using the medical eligibility referral form (MERF).

2. Early On® Training and Technical Assistance (EOTTA)

- Visit <u>www.eotta.ccresa.org/</u> for helpful resources including the *Early On* central directory. Find contact information for local *Early On* coordinators at www.eotta.ccresa.org/Coordinators.php.
- Request an Early On 101 presentation for medical personnel, or physician training, by contacting EOT&TA at eotweb@edzone.net or 1-866-334-5437
- To make a referral: contact 1-800-EARLY-ON or www.1800earlyon.org.
- To order materials online, visit www.1800earlyon.org.

Did you know? Federal law requires states to maintain and implement a comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families.

3. Early Hearing Detection and Intervention (EHDI) Program

- Visit <u>www.michigan.gov/ehdi</u> to find a statewide listing of pediatric audiology diagnostic/evaluation sites, and information for families of children with hearing loss including the Guide-by-Your-Side program.
- To make a referral or request in-service training: call the EHDI follow-up consultant at (517) 335-8878.

4. Genetics Resource Center

- Visit <u>www.migeneticsconnection.org/</u> to find information on Michigan resources and services related to birth defects and genetic disorders, including the online Michigan Genetic Support Group directory.
- To request a speaker: call 1-866-852-1247 toll-free or e-mail genetics@michigan.gov.
- **To request materials** including a birth defects "toolkit" and the free pamphlet on *Resources for Families of Infants and Toddlers with Special Health Care Needs*: Call 1-866-852-1247 toll-free or email BDRFollowup@michigan.gov.

5. Local Health Departments

- Visit <u>www.malph.org/page.cfm/108</u> to see a directory of contact information for city, county and district health departments.
- To make a referral: Contact the health department in the child's county of residence. Local health departments provide a variety of maternal child services and are the gateway for enrollment in multiple community-based systems and services including CSHCS, *Early On*®, MIHP and WIC.

6. Maternal Infant Health Program (MIHP)

formerly Maternal Support/Infant Support Services (MSS/ISS)

- **Visit** <u>www.michigan.gov/mdch</u> then search "MIHP" for more information about this program including a link to a provider directory for making referrals.
- Provides specialized care to Medicaid eligible pregnant women and infants using a multidisciplinary team approach. The dietitian, nurse, and social work team utilize interventions and linkages to community resources to provide support to high-risk mothers and infants. This program strives to decrease medical, social, and psychological risk factors that can lead to infant morbidity and mortality.

7. MIChild

- **Visit** <u>www.michigan.gov/mdch</u> then search "MIChild" to view the MIChild manual and answers to frequently asked questions as well as application information.
- Provides health insurance for children under 19 whose families meet income requirements
- For more information: Call 1-888-988-6300.

8. Newborn Screening Program

- **Visit** <u>www.michigan.gov/mdch</u> then search "NBS" for information about the newborn dried blood spot screening program for 48 disorders.
- Free web-based education module on NBS specimen collection with nursing CEUs: Visit www.training.mihealth.org/ and scroll down to the "New Featured Courses" section; click on the link to "Newborn Screening": then click on the "Sign Up" button to register as a site user.
- Free web-based presentation on expanded newborn screening/ inborn errors of metabolism: available at www.migeneticsconnection.org/newborn.shtml
- **To get patient results:** First check with your hospital laboratory or medical records department. If unavailable or infant's condition warrants immediate results, Fax to 517-335-0419 the following:
 - 1) Fax cover sheet with return secure fax #; 2) Authorization to release information signed by parent;
 - 3) Reason for request; 4) Mother and infant's first/ last names at time of birth; 5) Infant's date of birth.

9. Women's, Infants and Children (WIC) Supplemental Nutrition Program

- Visit www.michigan.gov/mdch then search "LOCAL WIC AGENCIES" to find useful links including a listing of local WIC agencies in Michigan counties.
- Provides: for patients meeting income guidelines—nutrition education, health care referral information, food coupons
- For more information: call the state WIC Office toll free at 1-800-942-1636.

Helpful Websites

American Academy of Pediatrics—Children's Health Topics: The Medical Home

www.aap.org/healthtopics/medicalhome.cfm

See the "Medical Home Quick Links" and "Medical Home Resources" sections.

American Academy of Pediatrics—The National Center of Medical Home Initiatives for Children with Special Needs

www.medicalhomeinfo.org/

See "Tools for Healthcare Providers" and "Training Programs and Materials" for a medical home training program that explains how to ensure CSHCN have a medical home in changing health care environments.

Center for Family & Infant Interaction www.uchsc.edu/cfii/

See the "Products & Resources" link.

Children with Special Health Care Needs Listserv digest

Subscribe by e-mail to cshcn-l@mchenet.ichp.edu

Family Village

www.familyvillage.wisc.edu

Site includes information on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature and much more. See the "School" section-"Early Intervention Resources"

Institute for Family Centered Care www.familycenteredcare.org/

See "Profiles of Change" for examples of pediatric hospital success stories and methods used to better serve children and their families during inpatient admissions.

Physicians

- CONSIDER the extra care, equipment and services a baby might need after discharge based on the type of birth defect and prognosis.
- HELP the family develop a longrange care plan for their child's special needs that outlines services, key contacts, and next steps for transition from hospital to home.
- LEARN more about communitybased service and support systems available for children with birth defects. Know how the referral process works in your hospital, and who can best assist in carrying out your recommendations.
- 4. SUGGEST referrals to community programs and services such as CSHCS, public health, or Early On® in addition to medical consults, and DOCUMENT your recommendations in the progress notes or on the appropriate form.*
- 5. **SPEAK** to your patient's family before discharge and encourage them to follow through with enrollment for available services as well as developmental assessment clinics/neonatal follow-up programs.
- HELP families of children with special health needs in your practice establish a medical home by providing comprehensive, coordinated care.

Nurses

- LEARN more about the service and support systems that are available to assist families of children with birth defects in your local community and statewide.
- MAKE sure your nursing unit keeps an updated list of key services, and DISTRIBUTE educational resources, contact information, and enrollment forms to families.
- 3. **KNOW** how the referral process works in your hospital. If included in your nursing role, **DOCUMENT** any information you provide to families in the progress notes or on the appropriate form* in the health record. If your role does not include making referrals yourself, then **CHECK** to make sure appropriate referrals have occurred as you review the nursing care plan.
- CONSIDER every encounter with parents as an opportunity to promote awareness of available services that might help their child or family.
- EMPOWER the family to ask questions about services their child may require after discharge, and to request referrals as appropriate.
- REMIND medical colleagues about community-based services if your facility requires physicians to initiate referrals.

Social workers & Discharge planners

- MAINTAIN a current listing/ directory of key state and local resources (including enrollment forms, as needed) available to assist families of children with birth defects, and share with other nursery personnel.
- IDENTIFY and DISCUSS with families the types of communitybased services and supports that are available to help meet the needs of babies with birth defects.
- PROVIDE pamphlets, educational resources, contact information, and enrollment forms to families; and make sure the information is easily accessible in the NICU, newborn nursery and parent waiting areas.
- 4. INITIATE referrals for appropriate services and DOCUMENT any information you provide in the baby's health record so that other caregivers can help to reinforce with the family the importance of following through with recommended services.
- ARRANGE in-service presentations on state and local service programs for newborn nursery and pediatric staff.
- 6. **CONTACT** the MDCH, Birth Defects Registry Follow-up Program at 1-866-852-1247 or BDRFollowup@michigan.gov to learn about the birth defects "toolkit" and order pamphlets for distribution to parents.

^{*} sample referral form included on next page

Service and Support Referral Record



Patient ID #							
Child's Name					Date of Birth		
Mother/Guardian/Foster Parent:					Date of Birth		
Father's Name					Date of Birth		
Street Address, C	city, Zipcod	e					
Phone (Home): Phone (Alternate):				E-mail:			
County of Residence				Referred to Inpatient Social Work/Care Coordination? YES NO			
Insurance Type: Medicaid? NO YES - Child's Medicaid #				Referred to Inpatient Pastoral Care? YES NO Other Insurance? NO YES			
Child/Family Referred to	Date of Referral	By Whom? (please initial)	Date of Enrollment	Child/Family Referred to	Date of Referral	By Whom? (please initial)	Date of Appointment or Enrollment
Children's Special Health Care Services CHSCS)				Genetics:			
Early On [®]				Outpatient Specialty Clinic:			
Women, Infants and Children WIC) Nutrition Program				Outpatient Specialty Clinic:			
Maternal Infant Health Program MIHP)				Outpatient Specialty Clinic:			
/isiting Nurse local public health or nospital system)				Support Group: (please specify)			
Healthy Start				Support Group:			
Medicaid or MIChild				Home Care Agency:			
II Department of Human Services DHS)				Medical Equip. Supplier:			
Supplemental Security Income SSI)				Other: (please specify)			
Newborn Screen Date			_	Repeat Newborn Screen		Date	
Hearing Screen	ng Screen Date				Repeat Hearing Screen Date		

 $\text{Left Ear} \rightarrow \text{ PASS REFER} \qquad \text{Right Ear} \rightarrow \text{ PASS REFER}$



www.michigan.gov/mdch